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ABSTRACT

This guide to early intervention services under Part H of Public Law 101-476 (the Individuals with Disabilities Education Act) is intended to aid state legislators who have the primary responsibility to create and shape programs under this Act. Three aspects of Part H legislation are stressed: (1) requirement of unprecedented coordination among health, social service, and education agencies; (2) focus on services to the child in the context of the family; and (3) the expectation that states will assemble a variety of funding sources to cover direct services. The first chapter provides an overview of the law including: eligibility, system components, program administration, identifying eligible children, case management, children and family rights, and program financing. The costs and benefits of early intervention for children, families, and society are considered in Chapter 2. Chapter 3 identifies policy considerations for lawmakers, Chapter 4, on financing early intervention services, identifies seven federal funding sources and discusses private health insurance. Four recommendations are offered: build a consensus among legislators and stakeholders; develop a plan to finance Part H services; ensure that programs are effective; and lobby the federal government for an increase of funds to support Part H. Appended are lists of organizational resources and acronyms. (DB)

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Early Intervention Services

FOR INFANTS AND TODDLERS WITH DISABILITIES

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- To improve the quality and effectiveness of state legislatures,
- To foster interstate communication and cooperation,
- To ensure states a strong, cohesive voice in the federal system.

The conference has offices in Denver, Colorado and Washington, D.C.

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Implementing Early Intervention Services

for

Infants and Toddlers with Disabilities

(P.L. 101-476, Part H)

by
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May 1991

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EXECUTIVE SUMMARY

Early intervention in the lives of infants and toddlers with developmental delays, and those at risk of developmental delay, substantially enhances development, provides essential support to the family, and minimizes future public-sector social costs. Studies indicate that states may recover, through savings in the costs of special education and institutionalization, between three and seven dollars for each one invested in early intervention services.

State legislators play a primary role in implementing state early intervention systems. Part H provides states with federal dollars to plan and implement early intervention services for children from birth through two and to their families. State policymakers retain primary responsibility to create and shape the programs.

FEDERAL LEGISLATION

Part H provides a five-year, discretionary-formula, grant program for states to plan and implement statewide, coordinated, comprehensive early intervention services for infants and toddlers with disabilities and their families.

Three aspects of the Part H legislation are particularly noteworthy:

- The law requires unprecedented coordination levels for funding and services among health, social service, and education agencies.
- Services are focused on the child in the context of the family.
- Because federal Part H funds are designated only for planning existing program coordination and filling gaps in services, states are expected to assemble a variety of funding sources to cover direct services.

The program is administered by a single agency designated by the governor assisted by a 15-member interagency coordinating council (ICC) that includes legislators, parents, service providers, and agency representatives. Although one agency has ultimate responsibility for the program, services are delivered by a variety of agencies and service providers, public and private.

Eligible children include those who experience developmental delays and those with diagnosed physical or mental conditions highly probable to cause delay. States have the option of also serving infants and toddlers who are medically and/or environmentally at risk for substantial delay if early intervention is not provided.

States are required to establish program components that include a definition of eligible populations, a finance system structure, and service and funding agreements among the various agencies that provide early intervention services.

During the third year of participation--which, at the state's option, was any time between July 1, 1989 and September 30, 1990--states must have adopted a policy that incorporates all program components. When applying for fourth-year funds, states must show that a statewide system is in place. During the fifth year of participation, the state's Part H services become an entitlement program, in which all eligible infants, toddlers, and families have a right to appropriate services.

Parents are encouraged to participate actively in the child's treatment program. Each child and his or her family receive a multidisciplinary evaluation and assessment. An individual family service plan (IFSP) is

devised to build on the family's strengths and fill the child's and family's needs. A case manager assists each family to obtain appropriate services identified in the IFSP process.

Policy Considerations for State Legislators

In their formal legislative function, state legislators determine who will be served and how the program will be financed and evaluated. They provide the oversight and leadership needed to implement a federal law that calls for unprecedented levels of coordination among health, social service, and education agencies.

Infant and toddler early intervention legislation exists in at least 15 states. Although state Part H policy can be established either through legislation, executive order, or state regulation, legislative policy development has several advantages:

1.) Legislation serves as a mandate for state agencies that remains constant despite changes in administration. Legislative policy directs agencies to cooperate and to access federal and private resources to fund early intervention services.

2.) Since legislators already determine program operating budgets for all key early intervention agencies, lawmakers can expedite the state appropriations process.

3.) Legislation focuses on early intervention efforts and gives the program statewide priority.

Legislators may also provide the informal leadership needed to build consensus on issues through their relationships with constituents, such as parents and advocates, legislative colleagues, and the state executive administration. Membership on the state ICC and relationships with constituents allow legislators to act as liaisons between executive, legislative, and public sectors to foster working alliances that establish the Part H system.

There are three areas in which legislators may be particularly effective: determining the scope of the program by defining the eligible population, coordinating the early intervention system, and structuring a plan to finance the Part H program.

Financing Early Intervention Services

Financing early intervention services is the most significant Part H challenge for state policymakers. Federal law establishes a structure to provide services but not the bulk of financial resources needed to deliver them. Instead, states are expected to assemble funding from a variety of sources. Further, as two-thirds of the states experience difficulty in balancing their state budgets for the current and upcoming fiscal years, new state revenues for comprehensive, statewide programs are scarce.

Legislators can direct state agencies to access federal and private resources for early intervention, which may include, but are not limited to, Medicaid, Maternal and Child Health Block Grants, Chapter 1, and private medical insurance. For example, Massachusetts legislators mandated private insurance coverage for early intervention services in 1990; while Texas legislators directed the Department of Human Services to access Medicaid and Chapter 1 funds for early intervention in 1989.

CHAPTER ONE: OVERVIEW OF PART H

INTRODUCTION

"Crack babies," low birthweight infants, toddlers with developmental delays, and children born with conditions such as Down's Syndrome and cerebral palsy face the prospect of a lifetime of physical and emotional challenge. Early intervention can replace gloomy futures with positive life outcomes. In fact, the earlier the intervention, the greater the benefits for children, their families, and for a society that bears the cost of their education and medical care. Studies indicate that for every dollar invested in early intervention, three to seven dollars are saved due to reduced need for special education or institutionalization, and prevention or remediation of developmental problems later in life.

In 1986, Congress responded to this information by adding Part H of Public Law 99-457 to the Education of the Handicapped Act (EHA), which changed to the Individuals with Disabilities Education Act (IDEA) in 1990. It authorizes the secretary of education to provide formula grants to states to plan and implement statewide coordinated, comprehensive, interagency, early intervention services for infants and toddlers with disabilities and their families. Part H provides federal dollars for a five-year planning period in which participating states develop and implement early intervention services. Funding for the first three years totaled $187 million. Congress must reauthorize Part H in 1991. In the fifth year of a state's participation, all infants and toddlers with disabilities, and their families, become eligible for state early intervention services.

Based on state experiences with early intervention programs and on research in child development, Part H requires an unprecedented level of coordination of services and funding sources within a fragmented, early childhood, service-delivery system. Part H focuses on the child within the context of the family and requires that the family actively participate in the child's assessment and treatment. State policymakers retain primary responsibility to create and shape programs. State legislation provides an important policy framework for development and expansion of early intervention programs. To date, at least 15 states have passed legislation to implement Part H. Most state statutes are modeled after the federal legislation with adaptations to reflect each state's unique circumstances and decisions about program parameters.

By implementing early intervention programs for infants and toddlers with disabilities and those at risk for developing delays states :

- Enhance the development of infants and toddlers with disabilities and prevent developmental delay,
- Reduce the costs of special education,
- Minimize the likelihood costly institutionalization,
- Enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.[1]

Under Part H, Congress provided financial assistance to states to:

- Develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all infants and toddlers with disabilities and their families;
- Facilitate coordination of payments for early intervention services from various public and private sources;
- Enhance the state's capacity to provide quality early intervention services and expand and improve existing services.[2]

WHAT IS EARLY INTERVENTION?

"Early childhood intervention means discovering that a child between birth and school age has or is at risk of having a handicapping condition or other special need that may affect his or her development and then providing services to the child and family to lessen the effects of the condition. Early intervention can be remedial or preventive in nature--remediating existing developmental problems or preventing their occurrence. Early intervention may focus on the child alone or on the child and the family together."[3]

WHO IS ELIGIBLE?

The Part H program is designed for children, birth to age three who need early intervention because they:

- Are experiencing **developmental deays** in one or more of the following areas: cognitive, physical, language and speech, psychosocial, or self-help;
- Have a **diagnosed physical or mental condition** that has a high probability of resulting in delay;
- At state discretion, are **at-risk** medically or environmentally **for substantial developmental delays** if early intervention is not provided.

Services are provided to the infant or toddler and to the family if services are needed to assist the child's development. Participating states are required to serve the first two categories of children and have the option of serving at-risk chiidren.

CHILDREN WITH DEVELOPMENTAL DELAYS. Each state must define the term "developmentally delayed." This is an important first step in the design of an appropriate service-delivery system. States are required to measure developmental delay with appropriate diagnostic instruments and procedures. The definition must specify the criteria used to determine a child's eligibility and outline how the state determines the existence of a delay in each of the five developmental areas listed above.[4] Legislation from Arkansas,[5] Oklahoma,[6] and South Carolina[7] specifically includes children with developmental delays in their statutes authorizing early intervention programs.

CHILDREN WITH DIAGNOSED PHYSICAL OR MENTAL CONDITIONS. This category includes children born with a genetic disorder, birth injury or serious chronic illness that has a high probability of delaying development. This enables states to serve infants and toddlers before they exhibit delays. Such conditions include Down's Syndrome and other chromosomal abnormalities likely to result in mental retardation, sensory impairment, fetal alcohol syndrome, and epilepsy.[8] State early intervention statutes from Arkansas, Oklahoma, and South Carolina specify this category.

CHILDREN AT RISK OF SUBSTANTIAL DELAY. At state option, infants and toddlers at risk of substantial developmental delays--if early intervention services are not provided--are eligible for services. Each state must adopt its own definition of *at risk* under the Part H program. States may include biological factors that place infants at risk for developmental delay, such as low birthweight, respiratory distress as a newborn, oxygen deprivation, brain hemorrhage, and infection.[9] States may also include environmental factors in their definitions of at risk. These include babies born to adolescent mothers and extreme family poverty. State planners devised more than 105 different biological risk factors and more than 58 environmental risk factors.[10] (See page 16) Some state statutes provide general authorization to treat at-risk children, for example Louisiana and Massachusetts.[11] Other state statutes specify which risk factors shall be used. Florida's statutory definition of *at risk* includes drug-exposed children and children whose family income is at or below 100 percent of the federal poverty level.[12] Mississippi serves at-risk children as the budget allows.[13] Colorado serves children of parents with developmental delays by executive order.

System Components

States must include these components in early intervention programs:

- o A state definition of "developmental delay,"
- o Finance policies and procedures,
- o A system for personnel development and standards,
- o Policy and procedures for contracting with service providers,
- o A central directory of services and providers,
- o Timetables for serving all eligible children,
- o A public awareness program,
- o A system to locate eligible children,
- o Procedures for evaluation and assessment,
- o Individualized family service plans,
- o Procedural safeguards,
- o Interagency agreements,
- o Procedures for resolving systemic complaints,
- o Data collection,
- o Supervision and monitoring of programs.

During their third year of participation, states must adopt a policy that incorporates all components. When they apply for fourth-year funds, states must show that a statewide system is in place. As of April 1, 1990, 11 states have received fourth-year funds: Colorado, Hawaii, Idaho, Illinois, Maryland, Michigan, Montana, Nebraska, Nevada, North Carolina, and Texas. During the fifth year of a state's participation, Part H early intervention services become an entitlement program. As such, all eligible infants and toddlers and their families have a right to appropriate services.

Program Administration

Primary responsibility for Part H planning and implementation is located in a single state agency designated by the governor. (See Table 1) States have chosen different methods to administer programs, with lead agency designation split among health, education, and social-services agencies. Maine, Rhode Island, and Texas designate an interagency coordinating entity as the lead. Maryland's Part H program is directed by the Governor's Office of Children and Youth.

Part H legislation also states that the lead agency is accountable for the entire program. Other agencies that currently fund and provide services for handicapped infants and toddlers continue their responsibilities and work with the lead agency to design an integrated service-delivery system. The lead agency's major functions include service delivery, supervision of other agencies that deliver Part H services, interagency funding and service coordination, and interagency dispute resolution. The lead agency must devise agreements with other relevant state agencies that detail the fiscal and program responsibilities of each agency. A major task for state planners is to link existing services and identify and fill gaps in service delivery.

Each state must establish a 15-member ICC, to advise and assist the lead agency. The council includes legislators, parents, service providers, and agency representatives. The council assists the lead agency to identify and coordinate funding sources and delegate financial authority to the appropriate agency. The council may also facilitate interagency agreements.

Office of Special Education Programs
Part H Allocations

State	*FY90 Allocation*	*State*	*FY90 Allocation*
Alabama	1,163,960	New Hampshire	388,764
Alaska	388,764	New Jersey	2,216,127
Arizona	1,249,449	New Mexico	519,508
Arkansas	677,333	New York	5,273,988
California	10,061,348	North Carolina	1,854,445
Colorado	1,025,863	North Dakota	388,764
Connecticut	914,070	Ohio	3,077,589
Delaware	388,764	Oklahoma	894,342
District of Columbia	388,764	Oregon	762,821
Florida	3,544,488	Pennsylvania	3,169,654
Georgia	2,031,998	Rhode Island	388,764
Hawaii	388,764	South Carolina	1,045,591
Idaho	388,764	South Dakota	388,764
Illinois	3,445,848	Tennessee	1,348,089
Indiana	1,551,947	Texas	5,786,920
Iowa	723,365	Utah	683,909
Kansas	743,093	Vermont	388,764
Kentucky	979,831	Virginia	1,782,108
Louisiana	1,400,698	Washington	1,407,274
Maine	388,764	West Virginia	427,443
Maryland	1,440,154	Wisconsin	1,387,546
Massachusetts	1,663,739	Wyoming	388,764
Michigan	2,702,755	Puerto Rico	1,361,241
Minnesota	1,288,905	American Samoa	120,662
Mississippi	789,125	Northern Marinas	80,441
Missouri	1,453,306	Guam	321,764
Montana	388,764	Virgin Islands	241,323
Nebraska	460,323	Palau	31,010
Nevada	388,764	Secretary of the Interior	971,911
		Total	**$79,520,000**

The U.S. Department of Education's Office of Special Education Programs (OSEP) administers Part H at the federal level. A federal ICC for the Part H program was established to improve collaboration among federal agencies that play a role in early childhood and family services.

FINDING AND HELPING ELIGIBLE CHILDREN AND FAMILIES

Four mechanisms to bring eligible children and their families into the system are established under Part H:

- A public-awareness program,
- A comprehensive child-find system,
- A central directory,
- A data collection system.

Twenty-nine states have adopted public awareness programs to educate the public about the importance and availability of statewide early intervention programs.[14] The child-find system, developed in 32 states, is designed for hospitals, physicians, parents, child care programs, and other providers to identify and refer children for evaluation and assessment.[15] The central directory includes information on public and private early intervention services, resources and experts available in the state, research and demonstration projects conducted in the state, and professional and other groups that provide assistance to eligible children and their families. Directories have been developed in 36 states.[16] Data collection systems compile information on the number of infants and toddlers in need of early intervention services and their families, the number served, and the types of services provided. Texas has the most fully developed system in place.

Once children are referred, a case manager is assigned to each family to coordinate evaluations and assessments. Each child is given a timely, comprehensive evaluation to determine eligibility for early intervention services. Once deemed eligible, a multidisciplinary assessment identifies:

- The child's unique needs,
- Family strengths and needs related to the child's development,
- The nature and extent of early intervention services needed by the child and his or her family to meet the identified needs.[17]

Any assessment of the family must be voluntary.

Each child and family participates in the formulation of an IFSP that acts as a blueprint to meet the specific needs of the child and family. The IFSP must outline specific child and family goals; describe the criteria, methods, and time frame for evaluating goal attainment; and specify the services needed to meet each goal. The plan must be completed within 45 days of referral and reviewed periodically to determine progress toward its goals.

Contents of the Individual Family Service Plan (IFSP)

- *A statement of the child's developmental status in each of the five specified developmental areas,*
- *A statement of the family's strengths and needs related to enhancing the child's development,*
- *A statement of the major outcomes expected to be achieved for the child and family, with the criteria, procedures, and timelines for measuring progress,*
- *A statement of specific early intervention services necessary to meet the child's and family needs,*
- *A statement of other services, including medical and health care, that the child or family needs but are not required by Part H,*
- *The projected starting dates for services and their anticipated duration,*
- *Appointment of a case manager from the profession most immediately relevant to the child's or family's needs,*

- *The steps to be taken for transition to preschool special education or other services appropriate for the child upon reaching age three.*

CASE MANAGEMENT

Parents of special needs infants and toddlers are often overwhelmed and unfamiliar with the wide selection of service providers and professionals. They may be uncertain about which services are appropriate for their child. Case managers help families work with service-delivery systems to obtain appropriate assistance. The case manager must be knowledgeable of early intervention services and able to assist interagency service delivery.[18] Thirty states have developed procedures for case management.[19] While parents may not be named as case managers, they do have a significant role. Parents must be actively involved and decide the extent to which they will participate in and receive services.[20]

What Do Case Managers Do?

- *Coordinate evaluations and assessments,*
- *Facilitate and participate in the IFSP process,*
- *Assist families to identify available service providers,*
- *Coordinate and monitor delivery of services,*
- *Inform families about advocacy services,*
- *Coordinate medical and health providers,*
- *Facilitate the development of a transition plan to preschool services, if appropriate.*[21]

PROVIDING PART H SERVICES

Part H provides early intervention services under public supervision, designed to meet the child's needs in five developmental areas. A wide variety of services should be provided, most at no cost to the families--except where related laws provide for family payments under a sliding fee scale. Services must be selected in collaboration with the family and tailored to its unique needs. To the extent possible, services must be provided in settings that include children without disabilities.

Services that conform to professional standards of practice must be provided under public supervision by qualified personnel who meet state requirements for each professional category. States have great flexibility to determine specific occupational categories of providers but still face a critical shortage of qualified personnel. In 1988, 88 percent of the states reported shortages of trained personnel to work with disabled children from birth to three years of age. Eighty-one percent expected that shortage to continue into the near future.[22] Most states also report a serious lack of personnel preparation programs.

Services included in the IFSP, if deemed appropriate:

- *Audiology,*
- *Case management services,*
- *Family training, counseling and home visits,*
- *Health services necessary to enable the infant or toddler to benefit from the other early intervention services,*
- *Medical services only for diagnostic and evaluation purposes,*
- *Nursing services,*
- *Nutrition services,*
- *Occupational therapy,*
- *Physical therapy,*
- *Psychological services,*
- *Social work services,*
- *Special instruction,*
- *Speech-language pathology,*

- *Transportation (direct and related costs of travel) necessary to enable the child and family to receive early intervention services.*[23]

Note: This list is not exhaustive.

CHILDREN'S AND FAMILY RIGHTS

States must protect the basic rights of children and families that participate in the program. Procedural safeguards must be established by the lead agency and used by all service-delivery agencies. Thirty-five states have developed procedural safeguards.[24]

Procedural Safeguards Required Under Part H

- *Parents may examine any early intervention records about the child and the child's family.*
- *Parents must receive written prior notice when the state or service provider proposes or refuses to initiate or change the identification, evaluation, placement, or provision of services to the child and the child's family.*
- *The family has the right to confidentiality of personally identifiable information.*
- *A surrogate parent must be assigned to a child whose parents or guardian are not known or cannot be found.*
- *The consent of the parent or guardian must be obtained in writing before evaluation and assessment and before the first provision of services.*
- *Services must continue during any complaint proceeding, unless the parents and agency agree otherwise.*
- *Regulations must provide for prompt and unbiased dispute resolution.*
- *Parents and the lead agency may bring a civil action in the courts to challenge an administrative finding.*
- *The lead agency must adopt written procedures for receiving and resolving any complaint from parents.*[25]

FINANCING EARLY INTERVENTION SERVICES UNDER PART H

Early intervention services may not be denied to people who can't afford to pay for them; federal law requires that selected early intervention services be provided at no cost to parents, except where federal or state laws authorize the use of a sliding fee scale.

There are four major sources of funding available for Part H planning and service delivery:

- Part H federal funds,
- Other federal funds such as Medicaid and Chapter 1,
- Private insurance coverage,
- State appropriations.

Part H federal funds are not meant to cover operating costs of state early intervention systems. Instead, Part H funds are primarily for planning and expansion. Several federal funding sources are already available for early intervention services. These include Medicaid, Maternal and Child Health Block Grants, Developmental Disabilities Basic State Grants, Even Start, Chapter 1, and Head Start. These monies may provide a significant portion of the resources needed to operate early intervention programs at the state and local level. The law clearly states that private health insurance benefits be used to pay for early intervention services under Part H. Several states are collecting substantial revenues from private insurance coverage to finance Part H services.

While states should attempt to maximize federal and private funding sources, state revenues are also required to fund adequately statewide early intervention programs. Due to the current fiscal conditions of the states--over half expect revenue shortfalls in fiscal year 1991--financing early intervention services will be a major barrier to implementing comprehensive programs.[26] (See chapter 4 for details on state financing options.)

CHAPTER TWO: THE COSTS AND BENEFITS OF EARLY INTERVENTION

Early intervention can have profound lifelong benefits for infants and toddlers with disabilities while containing the costs of special education and other services provided by the states.

Evidence based on over 50 years of research demonstrates that early intervention benefits the child, family, and society.

Child:

- Increases developmental and educational gains,
- Reduces the need for special education,
- Reduces the likelihood of being retained in grade,
- Makes the child indistinguishable from nondisabled classmates years after intervention.

Family:

- Increases the parent's ability to implement the child's program at home,
- Reduces the stress of rearing a disabled child.

Society:

- Reduces the costs of special education,
- Increases the productivity and contributions to society of the child with disabilities,
- Remediates and prevent costly secondary development problems.

Two groups of research support the early intervention public policy embodied in Part H. The first documents the physical, cognitive, and social competence of even very young infants; the second examines the benefits of early intervention for the child, family, and society. Both were detailed in the House report that accompanied the legislation.

INFANTS' ABILITY TO LEARN

Until recently, very young infants were viewed as passive participants in their world. New studies indicate that infants possess remarkable physical, cognitive, and social competencies. Research demonstrates that the minds and bodies of infants are responsive to, and can benefit from, early intervention.

Newborns actively perceive their sensory environment; they possess central and peripheral vision at birth and coordinate visual and auditory input by 30 months. Infants have control of complex and voluntary motor activity much earlier than once believed. Researchers such as Michael David Trout and Stanley Greenspan have documented the profound emotional development that also takes place during the first two years.

These abilities and behaviors enable an infant to develop interactive relationships with adults, thereby developing social competence very early in life. According to the House report, "there is clear evidence to suggest that sociable infants are capable of eliciting more stimulation from caregivers and that this heightened social competence leads to accelerated cognitive development."[27] Awareness of these competencies makes it more practical to develop earlier intervention programs for working with infants and toddlers with disabilities. "Since children have the capacity to learn at this early age, providing a stimulating, supportive, educational environment will maximize the child's potential and may prevent the emergence of more severe and costly problems later on."[28]

EFFECTIVENESS OF EARLY INTERVENTION FOR CHILDREN, FAMILIES, AND SOCIETY

Early intervention increases developmental and educational gains for the child, improves family function, and reduces the costs of special education and prevention of secondary affliction.

CHILDREN. The quality of life for infants and toddlers with disabilities, and those at risk, may be dramatically improved through early intervention. Infants with disabilities who receive early intervention show significant improvement in development and learning and a decrease in their need for costly special programs, compared with their peers who do not receive early intervention.[29]

In fact, the earlier the intervention, the more effective it is. Intervention strategies implemented at birth--or as soon as the disability or high risk factor is identified--generate greater developmental gains and reduce the likelihood of secondary afflictions.[30]

A recent study of premature, low birthweight babies provides a startling example of the benefits of early intervention for very young children. These infants constitute a significant number of infants at risk for developmental, behavior, and health problems. A 1990 study funded by the Robert Wood Johnson Foundation provided conclusive evidence that an extensive variety of services provided for the first three years of life significantly improves life outcomes for such children.

This randomized clinical trial showed that children receiving intervention:

- Had higher IQ scores, ranging from an average increase of 13.2 points for infants weighing 4.4 to 5.5 pounds at birth to an average of 6.6 points for infants born at less than 4.4 pounds;
- Had consistently fewer reported behavior problems;
- Were three times less likely to have IQ scores in the range of mental retardation than infants who did not receive the intervention.[31]

FAMILIES. Parents of a baby with disabilities often go through the stages of grief that characterize the unexpected loss of a loved one. Shock, despair, denial, and detachment may consume the parents' attention.[32] Parent-child interactions may be seriously impaired. Parents may feel overwhelmed and unable to cope with the child's special needs. Stress associated with raising an exceptional child may interfere with the family's well-being and hinder the child's development. In fact, families of children with disabilities are more likely to experience higher instances of divorce, suicide, and child abuse than the general population.[33] The benefit to families of disabled children is an important factor when weighing the value of early intervention programs.

Early intervention programs provide parents with the support and the skills necessary to cope with their child's special needs. Positive outcomes of family intervention include:

- Helping parents become the child's "first teachers" to implement the child's program at home,
- Improving the family's self-esteem,
- Reducing family stress by providing release time and improving the parent's attitudes toward themselves and the child.[34]

SOCIETY. Society has an interest in early intervention because appropriate intervention may reduce the need for costly special education programs, increase social contributions by the child, and prevent developmental and emotional problems that may require treatment at a later date.

Research shows that the earlier the intervention effort, the greater the cost savings. One study calculated the total costs of special education services provided to a child starting at different ages and continuing to age 18. The study focused on children who began early intervention services at birth, age two, and at age six. Total costs were less if early intervention services began at birth. By providing early intervention services as soon as possible, total costs are contained due to the remediation and prevention of developmental problems that would have required special services later in life.[35]

A 1988 review of the early intervention program in Texas measured program effectiveness for its impact on other state-supported programs. In the 1989 "Performance Report to the 71st Legislature," the Texas Interagency Council on Early Childhood Intervention (ICECI) concluded that successful intervention can reduce the need for costlier services at a later date. (See Table 2) The review found that in FY 1988, 10 percent of those children who left the program (approximately 370 children) achieved developmental proficiency and no longer needed state or local supported services. Another 9 percent (334 children) were referred to other preschool programs. Referral data indicate that as many as 704 children may have been diverted from special education services.

By providing early intervention services, the state planned to save $4.7 million in FY 1989. The average annual state cost for serving children through the ICECI program was $1,099 in FY 1988. The average cost for serving a child in special education is approximately $6,000 annually for ages three to six and approximately $2,000 per child thereafter. According to the report, "early childhood services appear to be an effective means of enhancing the developmental proficiency of delayed children while offsetting the need of costlier special education services at a later date. The annual cost avoidance is approximately one-fourth of the annual expenditure. Since the cost avoidance could continue throughout each child's 12 years of schooling, the expenditure would be covered in cost avoidance within four to five years. Another factor should be considered. Research indicates that children who receive early intervention services, but continue to need special education services, need less service than those whose intervention was postponed."[36]

Table 2.

Agency Funding and Subsequent Cost Avoidance

Fiscal Year 1989

Agency funding in millions	$15.3
Children served in comprehensive programs	8,606
Children diverted from additional service	775
Resulting annual avoided cost (in millions)	$4.7

Source: January 1989 Texas Performance Report to the 71st Legislature

Other studies document early intervention cost savings. A Tennessee study showed that for every dollar spent, seven dollars in savings were realized within three years. Cost savings resulted from the avoidance of special education and institutionalization.[37] A 1983 evaluation of Colorado's statewide early intervention program reports a cost savings of four dollars for each spent.[38]

The most extensive studies of the benefits of early intervention were conducted with disadvantaged preschool-age children. The Perry Preschool Study of three- and four-year-old children from low-income families in Ypsilanti, Michigan is the most frequently cited study of short- and long-term benefits of early intervention. Approximately half the children studied attended a well-designed, quality early childhood education program and the other half did not. Program curriculum stressed intellectual and social development and operated two and one-half hours a day, five days a week, for seven months. Teachers conducted home visits with the mothers for an hour and a half each week. Program staff received inservice training and extensive supervision. Costs, in 1981 dollars, were an estimated $4,818 per child for one year, $9,708 for two years.

Even at this level of expenditure, the program, as a long-term investment, returned six dollars for each dollar invested in the one-year program, and three dollars for each dollar invested in the two-year program. Savings came from reduced use by Perry Preschool children of special education services, reduced juvenile court contact, reduced welfare reliance, and increased employment and earnings. By age 19, half the former Perry Preschool children were employed, compared to 32 percent of the comparison group. Only 18 percent were on welfare, compared with 32 percent of the control group. School dropout rate (33 percent versus 51 percent), juvenile arrest records (31 percent versus 51 percent), special education use (15 percent versus 51 percent), and college or vocational school participation (38 percent versus 21 percent) all favored the Perry Preschool children.[39]

CHAPTER THREE: POLICY CONSIDERATIONS FOR LEGISLATORS

THE ROLE OF STATE LAWMAKERS

State legislators play a crucial role in implementation of Part H. Their formal legislative functions determine who is served and how the program is financed and evaluated. While Part H policy may be established by legislation, regulation, or executive order, at least half the states plan to establish policy by the legislative process to ensure policy continuity regardless of changes in the executive branch, to facilitate appropriation of state funds, and to establish statewide priority for the effort.[40]

Legislators may also provide oversight and leadership to implement a federal law that calls for unprecedented levels of coordination among health, social service, and education agencies. By participation on the state ICC and in their relationships with constituents, legislators act as liaisons between the executive branch, the legislature, and the public to foster working alliances to establish the Part H system. Legislators determine program operating budgets and statutory authority for all key early intervention agencies. Policy considerations related to program parameters, coordination of early intervention services provided by different delivery systems, and program finances concern lawmakers. This chapter covers coordination and program eligibility policy options; financing is discussed separately in chapter 4.

COORDINATING THE EARLY INTERVENTION SYSTEM

Because early intervention services are furnished by many types of providers and financed by multiple funding sources, there is a clear need for coordination among agencies delivering Part H services. To provide these services effectively, to minimize duplication, and to provide understandable and accessible service systems to consumers, states must create a multidisciplinary, comprehensive service-delivery system that coordinates both multiple services and funding sources.

All states now provide early intervention services to some infants and toddlers. However, services are generally provided in a haphazard and fragmented fashion. States must transform a hodge-podge of discrete programs into the coordinated system required by Part H legislation.[41] The law establishes some structures to promote coordination among various education, health-related, and social service agencies and professionals, but does not provide detailed directions on how to achieve it. Instead, state policymakers must solve this problem.

Human services coordination has been offered as an antidote to dwindling fiscal resources, ineffective bureaucracies, and duplication and gaps in services. While studies document that coordination has a positive effect on the continuity, accessibility and efficiency of service provision,[42] the process of collaboration has been likened to "dancing with an octopus--essentially an impossible task."[43] No model systems exist.

To foster coordination, state legislators may:

- o Provide leadership to the ICC,
- o Direct agency involvement in interagency agreements,
- o Structure programs to include local input and coordinate mechanisms.

THE INTERAGENCY COORDINATING COUNCIL. Under Part H, each state is required to establish a 15-member ICC made up of legislators, representatives of various agencies, service providers and parents. All states currently have an ICC in place.

By advising and assisting the lead agency to develop a coordinated system, the council was intended to be the primary mechanism for developing an interagency, coordinated, statewide service system. Although

the lead agency appears to have ultimate authority, The U.S. Department of Education cautions that the council should not be limited to "reacting to planning efforts completed solely by the lead agency."[44] In fact, as an independent group the council can tackle a variety of issues that would be problematic for any single agency.

Legislators ensure that the role of the ICC is understood clearly and its level of authority defined.[45] Such clarification enables the group to function productively. One issue to consider is the level of agency representative selected for participation on the council. This is an indication of the member's influence within his agency and impacts the effectiveness of the council on Part H planning. In Ohio and Rhode Island, commissioners are required to participate. Florida, Minnesota, and New Jersey require appointment of particular agency representatives.[46] In Florida, major division directors with considerable authority must participate.

States differ considerably about the level of agency personnel selected for council membership. In Pennsylvania, the deputy secretaries from the departments of education, health, and public welfare participate on the council. Representative Ron Cowell, chair of the House Education Committee, and chief sponsor of the state's Part H legislation, emphasizes that this high-level involvement by key agency decisionmakers was critical to obtaining a $20 million appropriation for the state's early intervention program. In contrast, while the Louisiana ICC drafted policy and accomplished some long-range planning, no agency heads--besides the division of administration--sit on the state council. Susan Batson, education section administrator for the Louisiana Department of Education, says this level of participation has worked well during the policy-development process since the council meets on a monthly basis and agency heads could not attend. She suggests that now that "big decisions" are needed, higher level representation will be needed to "get the work done."[47]

All states have at least one state legislator on the ICC and many have two--one from each chamber. As active participants, legislators have an opportunity to foster a climate of cooperation and lend credibility to early intervention issues.[48] They also lend a unique perspective on program and fiscal issues to the other members.

The Louisiana Experience

In Louisiana, former representative Theodore Haik was instrumental in the successful development of the state's early intervention program. As chair of the state ICC, Haik authored and sponsored the Part H legislation passed in 1989. He used the division of administration, which monitors budget information from all state agencies as well as the governor's office and other agency heads, to help pass the legislation. Mr. Haik's strong presence in the state capitol and chairmanship of the state ICC motivated other legislators to participate on regional councils throughout the state.

The Pennsylvania Experience

In Pennsylvania, Representative Ron Cowell, chairman of the House Education Committee, provided leadership on Part H issues. In 1983, approached by constituent groups of parents and providers, Cowell introduced a resolution on early intervention. The education committee held a series of public hearings on early intervention and concluded in a final report that early intervention made both fiscal and programatic sense. The report urged state fiscal support and chastised the administration for not collaborating on early intervention. Soon afterward, the governor appointed a key staff person to work with the departments of health, education, and public welfare to coordinate early intervention services. When the federal law passed in 1986, Pennsylvania was a model for other states. As a member of the Pennsylvania ICC, Cowell describes himself as "a bridge between the council, parents, agencies, and the legislature." His high profile allowed him to "challenge the agencies to do things better" and symbolized an ongoing legislative interest in the early intervention program. In 1987, work on Pennsylvania's Part H legislation began with a series of meetings to ensure representation of all interests. As chair of the education committee, Cowell kept the bill in committee until the wide-based consensus needed to build a

meaningful program was achieved. He worked with the departments of education, health, and public welfare to ensure administration support. The bill was signed December 19, 1990, and despite a $500 million state deficit, Pennsylvania currently appropriates $45 million for early intervention services for children to age 5 with $20 million devoted to the infant-and-toddler program. Pennsylvania is clearly ahead of the federal requirements; the state infant-and-toddler program is now an entitlement.[49]

INTERAGENCY AGREEMENTS. Part H requires the lead agency to enter into agreements with other agencies that deliver early intervention services. The agreements detail responsibilities for providing and financing early intervention services and outline how interagency disputes will be resolved.

While Part H legislation makes the lead agency accountable for the entire Part H program, the lead agency does not have the power to compel other agencies to cooperate, unless state law or regulations assign such authority.[50] Thus, legislators are in a unique position to promote interagency cooperation. Legislators can strategically outline administrative functions and responsibilities for the infant and toddler program. Legislators may also specifically mandate that state agencies cooperate with each other. In Texas, for example, the legislature amended appropriation bills to require agencies to work together to deliver early childhood intervention services.[51]

COORDINATION WITH LOCAL COMMUNITIES. An effective statewide early intervention program demands that both state and local levels coordinate service systems, providers, and consumer needs. Although federal legislation does not require it, several states created local interagency councils to facilitate coordination and ensure effective delivery of services to disabled children and their families in their home comunities. Several states, including California, Louisiana, Maine, Maryland, Minnesota, New Mexico, Ohio, Texas, Virginia, and Washington developed a local ICC system.[52] In fact, Maine, Minnesota, Ohio, and Texas' community-based interagency structures predate Part H. Washington and Ohio earmark some Part H funding for development and operation of local councils. Federal funds may also be earmarked for early intervention coordinators who provide technical assistance to the local interagency coordinating councils, as in Minnesota and Ohio. Currently, the Oregon legislature is considering legislation to create a structure of local councils to provide bottom-up integration of the early intervention program.[52]

DEFINING THE ELIGIBLE POPULATION

Defining the eligible population is crucial to implementing an early intervention program. Ultimately, state lawmakers are responsible for determining boundaries for eligibility--either directly by formal legislation, or indirectly by allowing the executive branch to make them. Eligibility decisions influence other policies related to finance, personnel, and services.

Legislators face two decisions:

- How to define "developmentally delayed,"
- Whether or not to serve "at-risk" children.

These decisions determine whether early intervention services are targeted solely at severely disabled, or are distributed to a larger group of children and families at moderate and mild risk levels.[53]

DEFINING DEVELOPMENTALLY DELAYED. Establishing a definition of *developmentally delayed* is one of 15 system components states must establish by the fourth year of program participation. It is critical because it serves as the foundation for others. (See page 3 for list of program components)[54]

According to a 1991 study by the Carolina Institute for Child and Family Policy, states progressed considerably toward a definition for target populations. Forty-two states have a fully developed definition.[55] For the most part, these closely mirror the language of the federal legislation and are general descriptions of the eligible population.[56]

DECIDING WHETHER TO SERVE AT-RISK CHILDREN. A major factor that influences the size and cost of a state's program is the decision whether to serve "at-risk" children in addition to the populations required by the federal act. Choosing to serve this group, or portions of it, increases the numbers eligible for service.

Children may be at risk of developmental delay for a number of reasons in two categories: biological and environmental. Biological risk indicators include factors such as low-birthweight, prematurity, and infection. Environmental risk includes details such as extreme family poverty, children of substance abusers, and children of teenage mothers. (See below)

At least 20 states include at-risk children in the eligible population. Fourteen serve both biologically **and** environmentally at-risk children. Five states are serving biologically at-risk children only and one state serves only environmentally at-risk infants and toddlers.[57]

Little agreement exists about the factors that place children at risk. In a 1991 report on states' definitions, 67 different factors were selected by only one state.[58] There is no consensus among the states on which environmental risk factors are most important. In the same report, 58 different criteria were listed. Twenty-seven different factors were selected by only one state.

EXAMPLES OF RISK FACTORS SELECTED BY STATES

Biological	**Environmental**
Abnormalities in tone	Adoption
Asphyxia with neurological	Child abuse/disturbed parent/ child relations
Birth trauma/infection/disease	Disabled family member
Chemically dependent mother	Homeless/transient family
Chromosomal abnormalities/ complications	Impaired psychological functioning
Complications at birth	
Congenital abnormalities/ syndromes	Lack of prenatal care
Congenital infections/neonatal meningitis	Limited maternal/family support
Established risk factors	Low income/economic disability
Growth deficiency/nutritional problems	Parent < 15
History of substance abuse	Parental concern about development
Infant/toddler acquired postnatal complications	Parental retardation/mental illness
Lead poisoning/toxins	Parental disability/health problems
Low Birthweight	Parental substance abuse
Metabolic disorders	Parental stress
Mother exposed to medications known to cause brain damage	Poor nutrition
Neonatal seizures	Substantiated abuse/neglect in home
Premature < 32 Weeks	Wardship of state
Prenatal infections (CMV, AIDS rubella)	
Sensory impairments	
Serious accident/near drowning	
Significant medical problems	
Small for gestational age	

Source: Carolina Policy, Definitions, April 1989

States also differ whether to use a single-factor or multiple-factor approach to determine risk. Six states use a multiple-factor approach--four more than in 1989. There is growing acknowledgment among policymakers that the single factor approach is limited and inaccurate for predicting developmental abilities.[59] Recent studies indicate that the effect of combined multiple risk factors is greater than the effect of any single factor.[60] The choice of a single or a multi-factor mechanism has cost implications since fewer children are likely to be identified as having multiple indicators.

MULTIPLE RISK FACTORS USED IN THREE STATES

Parental substance abuse coupled with poverty, abuse, and neglect;

Teenage parent coupled with poverty, abuse, neglect, and low birthweight;

Three or more of the following:

Low income/economic disability,
Parents' lack of high school education,
Sibling with disability,
Caretaker/18 or 19 at birth of child,
Three or more children in family.

Fiscal realities may force states that choose comprehensive programs to target resources to the most demonstrably needy infants and toddlers among the general at-risk group. It is the legislature's prerogative to outline appropriate targets for services when resources are scarce to ensure fair and consistent application of eligibility policies. Lawmakers may also limit service delivery for a potentially large at-risk population by other means. Mississippi, for example, has one definition for developmentally delayed and authorizes the agency to serve at-risk children as resources allow.[61]

CHAPTER FOUR: FINANCING EARLY INTERVENTION SERVICES

Financing early intervention services is the most significant challenge for state policymakers under Part H, which provides a loose structure for early intervention services but not the bulk of financial resources necessary for service delivery. States are expected instead to assemble a variety of funding from different sources. Part H federal funds are to be used to plan and coordinate existing programs, mobilize financial resources, and fill gaps in services. (See Table 3 for state allocations)

Two thirds of the states experience difficulty balancing state budgets for the current and upcoming fiscal years,[62] with the consequence that obtaining new state revenues for comprehensive statewide, early intervention programs is formidable. Fortunately, several funding sources are already available to states for early intervention for infants and toddlers with disabilities and those at risk. These consist of federal, state, and private sources:

- State appropriations;
- Federal sources from programs such as Medicaid, Maternal and Child Health Block Grants, Chapter 1, Even Start, and Part B of the Individuals with Disabilities Education of the Handicapped Act;
- Private medical insurance.

In the near term, budget concerns encourage lawmakers to seek more federal and private sources of funding for early intervention services. Program accountability is important to ensure scarce fiscal resources are used effectively. Although the federal act does not require program evaluation, such accountability measures are necessary to support program development and expansion. To illustrate both points: the Texas legislative budget board recently analyzed whether the state's early intervention program is cost effective and recommended its expansion by increased access to federal funds. The board, chaired by the lieutenant governor and composed of representatives from both chambers, designs the state budget. The board reviews agency programs for efficiency and effectiveness. In its 1987 report to the legislature, the board analyzed the early childhood intervention program from the fiscal point of view, outlining its cost effectiveness. The reports were submitted to the Senate Finance and House Appropriations committees, whose members recognized the importance of the program. In the same year, the legislature attached a rider to an appropriations bill that directed the department of human resources to access Medicaid and Chapter 1 funds for early intervention services as recommended by the budget board.[63]

Oklahoma legislation requires agencies to submit a joint funding plan "to determine the most effective utilization" of federal, state, local, and private funding sources.[64] The legislation specifically requires amendments to expand the Medicaid state plan to include early intervention services for eligible children.

In January 1990, the Massachusetts legislature mandated private insurance coverage for early intervention services. Legislators recognized that private insurance coverage could help offset the cost of the state-run program. The law requires insurance companies to cover a range of medically necessary early intervention services provided by licensed personnel. Screening, assessment, home visits, and center-based visits are among the covered services. The bill sets a maximum benefit of $2,400 per year per child, with a lifetime cap of $8,000 for early intervention services.[65]

Despite the states' budget constraints, state revenues remain an integral part of a comprehensive, statewide early intervention program. State funds are required to purchase services for children and families who fail to meet the narrow eligibility criteria for federal programs, or who lack appropriate medical insurance. To date, the state financing commitment varies considerably from state to state. State appropriation levels range from $20 million in Pennsylvania, $100,000 in Indiana, to nothing in Maryland

Table 1.
Part H Lead Agencies

State	*Lead Agency*	*State*	*Lead Agency*
Alabama	Education	Nebraska	Education
Alaska	Health & Social Services	Nevada	Human Resources
American Samoa	Health	New Hampshire	Education
Arizona	Economic Security/DD	New Jersey	Education
Arkansas	Human Services	New Mexico	Health & Environment
California	Developmental Services	New York	Health
Colorado	Education	North Carolina	Health Resources/MH-MR-SA
Connecticut	Education	North Dakota	Human Services
Delaware	Education	Northern Marianas Islands	Education
District of Columbia	Human Services	Ohio	Health
Florida	Education	Oklahoma	Education
Georgia	Human Resources/MH-MR-SA	Oregon	MH for DD
Guam	Education	Palau	Education
Hawaii	Health (CCS)	Pennsylvania	Public Welfare
Idaho	Health & Welfare/DD	Puerto Rico	Health
Illinois	Education	Rhode Island	Interagency Coordinating Council
Indiana	Mental Health	Sec'y of the Interior (BIA)	Education
Iowa	Education	South Carolina	Health & Environmental Control
Kansas	Health and Environment	South Dakota	Education
Kentucky	Cabinet for Human Resources	Tennessee	Education
Louisiana	Education	Texas	Interagency Council
Maine	Interdepartmental Committee	Utah	Health
Maryland	Gov't Office/Children/Youth	Vermont	Education
Massachusetts	Public Health	Virgin Islands	Health
Michigan	Education	Virginia	MH/MR/SA
Minnesota	Education	Washington	Social & Health Services
Mississippi	Health	West Virginia	Health
Missouri	Education	Wisconsin	Health
Montana	DD	Wyoming	Health

Federated States of Micronesia and Republic of Marshall Islands are not eligible for this program.
Source: James J. Gallagher et al., *Major Policy Issues in Implementing Part H- P.L. 99-457 (Infants and Toddlers)* (Chapel Hill, N.C.): Carolina Policy Studies Program, Frank Porter Graham Child Development Center, University of North Carolina, October 1988, 32–33.

and Mississippi. Nonetheless, some experts argue that states underuse many federal financing options for early intervention services. The remaining sections of this chapter outline the most important sources of federal and private dollars for early intervention services of interest to state lawmakers serving on budget committees and legislative fiscal staff.

FEDERAL FUNDING SOURCES

Among the federal funding sources available to states for early intervention for disabled infants and toddlers are Medicaid, Maternal and Child Health (MCH) Block Grants, Developmental Disabilities Basic State Grants, Even Start, Chapter 1, and Part B of the Individuals with Disabilities Education Act. It is important to note, however, that states use most of the federal sources that have the potential to fund Part H programs to finance other state programs.

MEDICAID

Medicaid is an important funding source for early intervention services for two reasons:

- A high percentage of infants and toddlers with disabilities, and those at risk, are **Medicaid eligible**.
- A substantial range of early intervention services and administrative costs are covered by Medicaid.

Thus, federal Medicaid dollars can be used to cover between 50 and 80 percent of the costs of certain early intervention services for a significant number of infants and toddlers if states structure Medicaid plans accordingly. Some states are already positioned to use Medicaid funds. Many states need to invest a considerable amount of personnel time to adjust state Medicaid plans to access these federal funds for early intervention services. Because Medicaid is among the fastest growing state expenditures, lawmakers and fiscal officers may be reluctant to expand its use further; however, it generally benefits states to access open-ended entitlement funding for existing programs. Involving Medicaid representatives in the Part H planning process may expedite the process.

The potential use of Medicaid payments is demonstrated in Massachusetts, where over $3 million in Medicaid reimbursements is collected annually for that state's birth- to two-year-old early intervention program--25 percent of the funding for the total program in 1988.[66]

ELIGIBILITY. Low-income individuals may be deemed Medicaid eligible if they qualify as categorically needy, medically needy, or through the Omnibus Budget Reconciliation Act (OBRA) amendments of 1989.

> Categorically Needy. Individuals receiving public assistance from Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI).
>
> Medically Needy. At state option, Medicaid benefits may be extended to families and individuals who do not meet the financial eligibility limits for AFDC or SSI, but who lack resources to pay medical expenses. States may set medically needy income standards up to 133 percent of the state's AFDC standard. Under this provision states may provide coverage to non-institutionalized children with disabilities at the same rate that would have applied had the children been institutionalized. Thirty-nine states provide services to this group.
>
> OBRA Amendments. Effective April 1990, pregnant women and children to age six with family incomes up to 133 percent of the federal poverty line are Medicaid eligible. At state option, pregnant women and infants up to age one with family incomes up to 185 percent of the federal poverty level are Medicaid eligible.

A sizeable portion of Part H-eligible children are eligible for Medicaid as well. In Massachusetts, almost 40 percent of children enrolled in early intervention programs are Medicaid eligible. Nebraska estimates that 65 percent of its Part H eligible population could qualify for Medicaid assistance.[67]

BENEFITS. Services under Part H and those required or authorized by the Medicaid statute are nearly identical.[68] States can structure the state Medicaid plan to provide early intervention services through the mandatory benefit category, the optional benefit category, or both.

MANDATORY BENEFITS. Mandatory benefits are those that must be provided through the state Medicaid plan. States can structure their plan to provide most early intervention services required by infants and toddlers with disabilities through the mandatory benefits category. Relevant services include: Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), outpatient hospital services, and physicians' services.

EPSDT. Most early intervention services can be provided with federally matched dollars under the EPSDT program. (See page 24 listing of services) EPSDT provides Medicaid-eligible children with health screening, well-child care, and necessary treatment services. Routine screening and vision, dental, and hearing services must be provided at medically established intervals and whenever a health, developmental, or educational professional determines that an interperiodic exam is necessary. Any conditions, defects, or illnesses detected during these exams must be treated with Medicaid resources. Treatment is required whether or not the necessary services are covered under the state plan. (See case study for example) One advantage of using EPSDT to deliver early intervention services is the flexibility to provide screening services in a large variety of locations. For example, Colorado uses Head Start agency staff to conduct EPSDT outreach services.[69] However, EPSDT is underused nationwide for early intervention services. EPSDT cannot pay for non-licensed providers; consequently, some states, including Massachusetts and New Jersey, use other service categories to provide reimbursible services by non-licensed personnel, under the direction of a doctor.

Case Study

Thomas is 18 months old. He has not begun to walk and does not have a vocabulary appropriate for his age. His mother takes him to the health department for a health screening and checkup. The nurse-practitioner bills the visit as an EPSDT screen. Thomas has such serious delays that he is referred to the developmental center for a more thorough diagnostic assessment. It is discovered that Thomas needs extensive physical therapy to correct a muscle development problem in his legs. Short-term speech therapy is recommended to assist Thomas to build better early-language skills. Both the physical and speech therapy are covered services under EPSDT. Later, Thomas may need further care, such as braces for his legs; these too would be a covered treatment service.[70]

Outpatient Hospital Services. Twenty-two states provide unlimited outpatient hospital services, the remaining 28 place restrictions on certain types of services, including mental health and ancillary services or impose visit or duration limits. Eighteen states cover day treatment (three-hour or longer sessions) in outpatient hospital settings. Five states--Connecticut, Delaware, Maine, Massachusetts, and New Jersey--provide specialized intervention for young children with developmental delays through Medicaid-funded day treatment services. This benefit category reimburses comprehensive evaluations and assessments, for example.

Physicians' Services. Physicians' services include any services provided within the professions' scope of practice or under the *supervision* of a licensed physician. Services may be furnished in any setting including an office, the patient's home, a school, day care, outpatient or inpatient hospital, clinic, or nursing facility. Benefits under this category cover all services required by young children with diagnosed physical, sensory, or neurological problems. Twenty-six states allow recipients unlimited, medically necessary physician visits.

Other states limit either psychiatric and/or all other physician services. Forty-five states permit physicians to submit claims for services rendered in any setting. Services provided by other types of practitioners, under the supervision of a physician, are covered to varying degrees.

OPTIONAL BENEFITS. Many optional benefits may be structured to provide critically needed early intervention services. Relevant optional services include clinic services; rehabilitative services; case managment; physical, speech, and occupational therapy; and other licensed practitioners' services.[71]

Clinic Services. Clinic services are the primary means to finance comprehensive center-based services to infants and toddlers with disabilities. Forty-seven states provide them. Those that do not--Mississippi, Rhode Island, and Wisconsin--provide similar benfits under another benefit category. Clinic services are defined as "any preventive, diagnostic, therapeutic, rehabilitative, or palliative items or services provided to outpatients by a facility that is organized and operated to provide medical care by or under the direction of a doctor." Each state plan determines which services are available. Mental health clinics (available in 33 states), developmental disability clinics (available in six states), and school clinics (available in two states) are some of the services that may be included under this category. This benefit category pays for therapeutic day care. Connecticut defines schools as clinics under this option. The Hartford school district, for example, collected $300,000 during 1987--88 in Medicaid and other third-party payments.[72]

Case Management. Case-management services are designed to assist eligible individuals gain access to needed medical, social, educational, and other services. These can be targeted to certain subgroups, including disabled infants and toddlers. Case-management services available under Medicaid are strikingly similar to those required under Part H. Case management could be designed under a state's Medicaid plan to cover many of the interagency coordination functions essential to successful Part H implementation. Twenty-six states currently provide this optional benefit.

Physical, Occupational, and Speech Therapy. These are the most frequently delivered services in early intervention programs. Under Medicaid, such services must be prescribed by a physician and may be provided in any setting, including a home or school.

Other Practitioners' Services. Any medical or remedial care services provided by a licensed practitioner other than a physician may be reimbursed under this benefit category. States are required to cover certified pediatric and family nurse practitioners and may choose to cover services provided by social workers, psychologists, nurses, and nutritionists under the state plan.

Rehabilitative Services. Rehabilitative services are defined as "any medical or remedial services recommended by a physician . . . for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level." This benefit category is extremely flexible and offers considerable opportunities for financing non-traditional health and mental health services to young children with disabilities and their families.[73]

MEDICAID IN A NUTSHELL

Medicaid provides federal financial assistance to states for medical services furnished to certain low-income people. These are paid by a match of state and federal dollars. The federal share varies by state and ranges from 50 percent to 80 percent.

Medicaid works differently in each state based on the state plan approved by the federal government. States have great flexibility to determine who is eligible and what services will be provided. However, once these decisions are made, all eligible persons must receive services described in the state plan.

Benefits offered under Medicaid generally fall into one of two categories: mandatory and optional. All states must offer 10 core services. States can also choose to offer more than 32 optional services but once the decision is made services must be provided to all eligible persons. However, several exceptions to this rule allow states to provide some optional services to specific subgroups of people, including infants and toddlers with disabilities.

Early Intervention Services Provided by Federally Matched Medicaid Dollars

- Podiatrists
- Optometrists
- Chiropractors
- Other practitioners' services
- Private duty nursing
- Clinic services
- Skilled nursing facilities
- Emergency Room
- Personal care
- Transportation
- Case management
- Hospice
- Eyeglasses
- Diagnostic
- Preventative
- Rehabilitative
- Intermediate care facilities
- ICF for mentally retarded
- Inpatient psychiatric
- Christian Science nurses
- Physical therapy
- Occupational therapy
- Speech-language-hearing
- Prescribed drugs
- Prosthetic device

CHAPTER 1 PROGRAM

The Elementary and Secondary Education Act of 1965, Title 1, Chapter 1 provides basic grants to local education agencies (LEAs) to support supplementary compensatory educational services for educationally disadvantaged children. The program provides financial assistance to school districts based on the number of children from low-income families.

ELIGIBILITY. The program is designed to serve children, through grade 12, who are educationally disadvantaged and who reside in low-income areas. Preschool children and infants and toddlers may be included if they are developmentally delayed or have a physical or mental condition likely to result in delay. At-risk infants and toddlers are not eligible. School districts determine who is educationally disadvantaged and whether to serve preschool children.

SERVICES. About three-quarters of Chapter 1 services are composed of reading and mathematical instruction. However, other services such as language arts, and support services such as health and nutrition, guidance counseling, and transportation services can also be funded through Chapter 1. Local school districts determine which services to provide and may consider the needs of preschool children in program design.

FUNDING. Over $4 billion dollars was appropriated in FY 1990. Over $380 million was targeted to schools in very low-income areas. A small percentage is used for early intervention for infants and toddlers with disabilities. It is important to note that Chapter 1 funds finance the classrooms in which early intervention services may be delivered. Additional monies must be used to fund the early intervention services themselves. Massachusetts, New York, Pennsylvania, and Texas claim significant numbers of infants and toddlers under this program. In 1988-89, Massachusetts counted 4,451 infants and toddlers under Chapter, 1 while Pennsylvania claimed 3,653. In 1988, the Texas Education Agency authorized the use of Chapter 1 funds for children birth to three and payments amounting to $507 per child were collected for nearly 1,300 children.

MATERNAL AND CHILD HEALTH BLOCK GRANTS

The purposes of the MCH block grants parallel the aims of state early intervention programs and provide resources to accomplish mutual goals. For example, priorities for use of MCH block grants are to:

- Reduce the incidence of preventable diseases and disabling conditions among children and the need for inpatient and long-term services;
- Ensure access to quality maternal and child health services, especially for those with low incomes;
- Provide rehabilitation services for blind or disabled individuals under age 16 receiving SSI;
- Provide assistance to children in need of special health care services through efforts to locate them, ensure medical and other supportive services and care, and ensure availability of health care facilities.

The program has provided prenatal care to hundreds of thousands of low-income women and preventive, primary, and specialized care to millions of low-income children.

MCH block grants replace categorical grants under Title V of the Social Security Act in 1981 and match every three state dollars with four federal dollars. The federal block grant appropriation for 1990 totaled $541 million and represents a significant authorized funding increase from 1989.

ELIGIBILITY. States determine eligibilty for program services. States may charge fees for services, but not to low-income women and children. Sliding fee scales are used in many states.

SERVICES/BENEFITS. Like the state plan under Medicaid, state applications for MCH grants include a statement of program goals and objectives and of services to be provided. Examples of state services provided include screening and treatment of disabling conditions and support services such as case management and counseling. Home-based services such as home nursing and respite care, and training for families, are funded by MCH grants.

Services are generally provided through state health agencies and physicians on a fee-for-services basis and are usually clinic based. Most states coordinate MCH services; the state agency provides services that are Medicaid reimbursable.[74]

DEVELOPMENTAL DISABILITIES BASIC STATE GRANTS

This is a relatively small grant program authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 1990 to plan, coordinate, and deliver specialized services to persons with developmental disabilities. The program is much broader than early intervention for very young children, but states have the option to fashion their programs to serve this population. The purpose of the act is to provide opportunities and assistance for the developmentally disabled to enable them to achieve maximum potential through increased independence, productivity, and integration into the community.

States shape their program by creating a state plan that identifies existing gaps in services and establishes priority services areas. The only required priority service is employment. Among the other priority issues a state may choose to address are child development activities, case management, and family support services. Each area is significant to state early intervention programs for infants and toddlers. Funds may be used to enhance system coordination, conduct outreach activities for developmentally disabled persons to enable them to access services, and train persons with developmental disabilities and their family members to access services. Each of these activities is clearly related to Part H. The minimum state allotment is $350,000 and is available through the U.S. Department of Health and Human Services.

EVEN START

Even Start is a family-centered program that combines adult literacy, parent education, and early childhood education. Its aim is to involve parents in their child's development and to help parents be their children's first teacher, including parents of children with disabilities. The program is authorized by the Hawkins/Stafford School Improvement Act of 1988.

The program is designed to blend existing community resources for parent education, adult literacy, and early childhood care and education. Even Start funds are intended to build on these resources to create a complete program. Consequently, coordination with programs under the Individuals with Disabilities Education Act (IDEA), Head Start, adult literacy, and Chapter 1 is required.

ELIGIBILITY. Parents must be eligible for participation in an adult basic education program; children ages 1 to 7 must reside in an elementary school attendance area with a high concentration of children from low-income families, also a Chapter 1 criterion. From the pool of eligible families, service providers choose those most in need. Children identified as needing special education services are eligible.

SERVICES. Even Start services with relevance to state early intervention programs:

- Instructional programs that train parents to support the educational growth of their children and prepare children for success in regular school programs,

- Support services such as child care and transportation--only when unavailable from other sources.

Services may be provided in either a center-based or home-based manner. In fact, the U.S. Department of Education prefers home services when possible.

FUNDING. For FY 1989, $148.2 million was appropriated and funneled to the states. States match federal funds with 10 percent, 20 percent, 30 percent, and 40 percent in the first, second, third, and fourth years of the program. In-kind services and IDEA funds may be used for the state match. While the appropriation is under $50 million, grants are made directly to LEAs. No state receives less than $250,000, or 5 percent.

CHILDREN WITH DISABILITIES

The Children with Disabilities Program authorized by the Hawkins/Stafford School Improvement Act of 1988 provides educational support in state-operated or state-supported facilities and transferees from such facilities to special education classes in the local school system. Grants are awarded to state education agencies for programs to supplement the special education needs of children with disabilities and the early intervention needs of infants and toddlers. Under this program states may acquire equipment and instructional materials, employ and train personnel, identify and involve children with disabilities and their families in a broader range of services. This program emphasizes its relationship with the Education of the Handicapped Act, including Part H.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT, PART B

Public Law 101-476 requires that a free, appropriate, public education be provided in the least restrictive environment by state and local education agencies to all school-aged children (3-21) with disabling conditions. States may use Part B funds for early intervention for infants and toddlers with disabilities. Nebraska, for example, uses Part B money to expand services downward to birth. In 1990, Congress reauthorized IDEA and broadened use of discretionary programs to include services for children aged birth to three. For example, infants and toddlers exposed in utero to substance abuse are now eligible for services under the early education program.

PRIVATE HEALTH INSURANCE

Congress intended states to access private health insurance reimbursements to help fund Part H. In fact, Medicaid law requires states to seek private insurance payments before turning to Medicaid payment. In addition to many of the home health care services required by medically fragile children, the components of early intervention services typically covered by private health insurance policies include speech therapy, occupational therapy, and physical therapy.

Under Part H, parents may be asked to pay for some services based on a sliding fee scale and the ability to pay, when this is established by federal or state law. In these cases, parents may be asked to contribute to the cost of any deductibles and/or co-payments. Some state programs pay premium charges for clients. Administering the program presents challenges to service providers and requires them to determine what type of private health insurance is carried by the families of children enrolled in early intervention programs. Whenever a service is provided to a child that is covered by the child's insurance, a bill is sent to the insurance company for reimbursement.

Agencies providing early intervention services have been reluctant to bill private insurers. Collection of money from private health insurers requires substantial effort. Providers need a well-organized system to collect information from parents about the types of coverage, both for billing and for dealing with the questions of health insurers. Colorado, Connecticut, Illinois, and Utah are systematically collecting revenues from private insurance coverage to help support programs for disabled children.[75]

Revenues from private health insurances can substantially increase the total amount of money available to fund state early intervention programs. Illinois operates a third-party billing system on a regional basis. The Regional Education Center serves over 8,000 children in its early intervention program. A third-party billing system was established over the course of a year and receipts from Medicaid and private insurers now averages over $1,000 per day. In Connecticut, school districts that provide early intervention services pay the deductible for the private insurance carried by parents.[76] Massachusetts' legislators recently mandated that private insurance companies cover the costs of early intervention services. Budget constraints continue to encourage the development of public/private partnerships in the states to finance early intervention services.

CONCLUSION

Early intervention services for disabled and at-risk infants, toddlers, and their families improve the lives of children and families and produce long-term benefits to states. These include reduced need for costly special education classes and increased productivity and social contributions by early intervention "graduates."

Part H is designed to assist states to build and implement an early intervention system. Translating policies embedded in the federal law into action, however, is complex and costly for the states. The federal legislation requires an unprecedented level of coordination among health, education, and social services agencies, yet provides no concrete blueprint for achieving that goal. Although Part H funds are available to plan state early intervention systems, states are expected to shoulder the bulk of program-operating costs either directly or by accessing existing, though often strained, funding sources such as Medicaid.

With over half of the states facing revenue shortfalls during the upcoming fiscal year, legislators must make tough decisions. If difficult policy and funding choices are confronted by state legislators in the formal legislative process, priorities are set openly with public input; and consistent guidelines for eligibility, program operation, and equitable access to services are established.

Legislators play a crucial role in implementing successful early intervention programs. State lawmakers are in a unique position to coordinate agencies and build the necessary consensus for effective statewide, comprehensive service system. State lawmakers not only set state funding priorities and establish statutory program authority, they also represent the interests of the families and advocates within their home communities. Legislators possess the skills and authority to forge a financing plan for Part H services. Lawmakers can direct state agencies to access federal and private funds available for Part H services and authorize state appropriations for early intervention programs.

All states are currently participating in Part H. Fifteen states have legislation establishing Part H services as a statewide priority. Eleven are in the fourth year of program operation and have established policies to implement program components required under the federal law.

RECOMMENDATIONS FOR EFFECTIVE IMPLEMENTATION

1.) Build a consensus among legislative colleagues, the executive branch, advocates, and parent groups to shape a program that benefits all stakeholders and generates broad-based support within the legislature.

2.) Develop a plan to finance Part H services. Access federal and private funding sources to offset state costs. Include Medicaid and private insurance representatives in the financing planning process.

3.) Ensure that programs are effective. Given the tough economic conditions in most states, program evaluations can provide data to bolster support from legislative colleagues and the executive branch. Furthermore, evaluations of different program models can pinpoint which programs best meet the unique needs of individual states.

4.) Lobby the federal government for an increase of funds when Part H is reauthorized. Part H is due for reauthorization in 1991. Help educate federal policymakers about the need for increased federal dollars and for incentives within the program to encourage states to locate and serve more children.

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APPENDIX A

RESOURCES

National Early Childhood Technical
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(919) 962-7374

National Center for Clinical Infant Programs
2000 14th Street, North, Suite 380
Arlington, Virginia 22201-2500
(703) 528-4300

Mental Health Law Project
2021 L Street, NW, Suite 800
Washington, D.C. 20036
(202) 467-5730

U.S. Department of Education
Office of Special Education and
Rehabilitative Services
330 C Street, SW, Room 4617
Switzer Building
Washington, D.C. 20202
(202) 732-2028

The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
(703) 620-3660

National Association of State
Directors of Special Education (NASDSE)
2021 K Street, NW, Suite 315
Washington, D.C. 20006
(202) 296-1800

United Cerebral Palsy Associations, Inc.
1522 K Street, NW, Suite 1112
Washington, D.C. 20005
(202) 842-1266 or 1-800-872-5827

APPENDIX B

GLOSSARY

AFDC	Aid to Families with Dependent Children
EHA	Education of the Handicapped Act
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
ICC	Interagency Coordinating Council
IDEA	Individuals with Disabilities Education Act
ICECI	Interagency Council on Early Childhood Intervention
IFSP	Individual Family Service Plan
LEA	Local Education Agencies
MCH	Maternal and Child Health Block Grants
OBRA	Omnibus Budget Reconciliation Act
OSEP	Office of Special Education Programs
SSI	Supplemental Security Income

About The Author

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